

PLASMINOGEN DEFICIENCY



FOUNDATION

Mental Health Toolkit

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Plasminogen Deficiency Foundation

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Overview

Type 1 plasminogen deficiency, or PLGD-1, is an ultra-rare disorder in which a patient does not produce enough of the clotting factor plasminogen. “Ultra-rare” means that there are fewer than 1 in 50,000 patients known to have this disorder. PLGD-1 is also a chronic disorder, meaning it is present throughout a patient’s lifetime. In addition to the physical symptoms of this disorder, emotional and mental health can be affected. This guide is intended to help you navigate mental health challenges that can occur when living with a chronic, ultra-rare disorder like PLGD-1.

Goals

1. To assist patients and families who have been diagnosed with PLGD-1 to consider their mental health as part of their overall treatment plan
2. To provide patients living with PLGD-1 with resources to support and improve their mental health

Medical Disclaimer:

The contents of this toolkit are intended for informational and educational purposes only and are not a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified healthcare provider with any questions you may have regarding a medical condition or your mental health. Never disregard professional medical advice or delay in seeking care because of something you have seen or read in this toolkit. If you think you may have a medical or mental health emergency, call your doctor or emergency services immediately.

Mental Health Forum: Managing Chronic and Ultra Rare Disease

I. How do chronic medical conditions impact the mental health of children and adolescents?

Chronic medical conditions can impact the mental health of children and adolescence in very serious ways. Every child is different, and as such their particular neurochemistry varies drastically from patient to patient. Particular concern should be given to patients who have a family history of mental health issues, such as depression, anxiety, or any other mood disorder.

Dealing with a chronic medical condition will be stressful for your family in any circumstance. And emotional and psychological symptoms can co-occur with chronic medical conditions, such as isolation, confusion, and sadness, amongst many others. Frequent bouts of illness requiring surgeries and hospitalizations can put patients under extreme stress, which can lead to the development of mental health symptoms as well. We know that enduring trauma and medical trauma can predispose the growing child's brain to depression and anxiety, and of course, Post-traumatic Stress Disorder.

It is important to check in on your child or adolescent frequently and ask them how they are doing and how they are feeling. It is also important to offer them extra resources and support such as psychotherapy, medication management if indicated, or group therapy where they can meet other patients suffering from chronic illness.

Community is so important; and exposing your child or adolescent to others who are suffering with rare disease is very helpful and helps them not feel alone.

Everyone's journey is different, but supporting each other along the way can make all the difference in the world in your child's development and their future success as they navigate the difficult waters of rare disease.

II. What are the signs to look out for if my child or adolescent is struggling with mental health issues?

It's important to always monitor your child or adolescent for symptoms of depression, which could look like--low energy, changes in appetite, changes in sleep, depressed mood, feelings of hopelessness or worthlessness, or in severe cases, thoughts of wanting to harm themselves. This could include self-injurious behaviors or even suicidality.

Symptoms of anxiety can present with excessive worry, or in some cases having panic attacks. Panic attacks differ from patient to patient, but in general people can experience a racing heart, difficulty breathing, sweating, and a general foreboding feeling.

As it is very common for patients with rare disease and chronic illness to go through multiple traumatic events, especially medical trauma, it is crucial to look out for symptoms of Post-traumatic Stress Disorder. The symptoms might include vigilance and hyper vigilance, intrusive thoughts, and intrusive memories of traumatic events. They may also include hyperreactivity to distressing stimuli and nightmares. If you notice these symptoms in your child, it is important to get them help right away and open the door to communication so that they do not feel alone and can seek treatment.

III. What are some practical ways to help patients suffering from rare disease to practice behaviors that will facilitate self-confidence?

Unfortunately, many patients who suffer with Plasminogen Deficiency have gone through very traumatic and often disfiguring changes in their physical appearance throughout their journey with the disease. Often these symptoms occur at very young ages and so this trauma starts very young.

Other children can be cruel towards others who look different and that can be very painful for children and their families if they are subject to bullying and or ridicule. The nature of suffering with a rare disease makes people feel isolated and different. This in and of itself can lead to loneliness and feeling less than and defective in some way.

It is important to help your child feel self-confident and self-assured. Helping them understand that everyone has their unique differences in some way or another can be comforting. Helping your child to develop their identity as separate from their illness is crucial. Practical examples of that could be facilitating a hobby, or an activity outside of school. Helping them to build their community outside of home and school can give you and your family much needed support and encouragement.

It can also be helpful to approach a child's teacher or fellow students at school and help them understand the differences in your child's appearance so that they can be supportive and encouraging and help them to connect with others and make close friendships.

IV. What are some suggestions to facilitate self-advocacy?

When dealing with a very rare chronic illness, self-advocacy is crucial. Patients are often in situations where they are the ones that know the most about their disease. So they are often put in the uncomfortable position of having to educate their physician about what is best for their bodies and their treatment.

Encouraging your child or adolescent to speak boldly about their condition with their medical team and encouraging their medical team to get educated is very important. If they feel something is off, they must have the courage to express themselves and help their treatment team get the knowledge they need.

Likewise, encouraging your child or adolescent to be their own best advocate in social situations is a wonderful skill that they can possess. If there is something going on that they don't feel comfortable with it is important for them to express themselves and feel confident to do so.

Patients with very rare, chronic illnesses often have special needs that differ from their peers. Therefore, they may not feel comfortable with some situations the way others would. They also might be more cautious in taking risks that expose them to viruses or other illnesses. It is important to help them not feel embarrassed or ashamed to communicate their needs.

V. More Resources

The **National Bleeding Disorder Foundation** has wonderful mental health resources for patients with different types of bleeding and coagulation factor disorders. The list of resources can be accessed here:

<https://www.bleeding.org/sites/default/files/document/files/Mental-Health-Resource-List.pdf>

Mental Health Hotlines: If you or a loved one are experiencing a life-threatening situation or having thoughts of self-harm or harming others, seek immediate assistance by calling 9-1-1 or going to the nearest emergency department or be accessing these hotlines:

- 988 Suicide and Crisis Lifeline: dial 988
- National Alliance on Mental Illness (NAMI): 1-800-950-NAMI (6264)
- The Trevor Project: 24/7 crisis support services to LGBTQ young people, 1-866-488-7386
- Substance Abuse and Mental Health Services Administration (SAMHSA): 1-800-662-HELP (4357)

Local or virtual support groups: local or virtual support groups composed of other patients who are experiencing a similar situation can be immensely helpful. Consider these options for virtual support groups:

- Center for Chronic Illness (CCI): CCI promotes well-being and decreases isolation for those impacted by chronic illness through support and education;
<https://www.thecenterforchronicillness.org/>
- Rareminds: Mental health for the rare disease community;
<https://www.rareminds.org/>

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